Explanatory Notes – Childhood Cancer Profiles

A set of indicators have been established to measure progress towards the goals of the Global Initiative for Childhood Cancer. As a baseline in the Americas region, a set of Childhood Cancer Profiles has been prepared for each country, as well as regional and subregional profiles, using thekey set of indicators.

This is an explanation of the data used to produce the Childhood Cancer Profiles for the Region ofthe Americas. The data definition and sources are described and organized according to the sections presented in the Profiles, which include 1) burden of childhood cancer; 2) survival and cancer registration; 3) health system response for childhood cancers; and 4) palliative care capacity.

The sources of data vary by indicator using the latest available year. Data on cancer incidence andmortality data are taken from the International Agency for Research on Cancer, in the global cancer observatory from 2020. Mortality trends, however are calculated using cancer mortality from the WHO Mortality Database.

Country specific data are presented in each country's Profile. For the region of Latin America andCaribbean, as well as the subregional Profiles, data are collated for the respective grouping of countries, as described in this explanatory note.

Burden of Childhood Cancer

1. Number of new cases of childhood cancer
   Definition = number of new cases of childhood cancer (ICD-10 codes C00-C97), ages 0-19years
   Year = 2020
   Data source = Global Cancer Observatory,
   IARC, 2020https://gco.iarc.fr/today/home

2. Number of childhood cancer deaths
   Definition = number of childhood cancer deaths (cause of death, ICD-10 codes C00-C97),ages 0-19 years, registered each year
   Year = 2020
   Data source = Global Cancer Observatory,
   IARC, 2020https://gco.iarc.fr/today/home

3. Percentage of all childhood cancer cases in the Latin America and Caribbean (LAC) region Definition = (Number of new cases of childhood cancer (ICD-10 codes C00-C97), ages 0-19years for the country/ Number new cases of childhood cancer (ICD-10 codes C00-C97), ages 0-19 years for the LAC region)*100
   Year = 2020
   Data source Global Cancer Observatory,
   IARC, 2020https://gco.iarc.fr/today/home

4. Percentage of all childhood cancer cases in the world (*calculated only for LAC region)
   Definition = (Number of new cases of childhood cancer (ICD-10 codes C00-C97), ages 0-19 years for the LAC region/ Number new cases of childhood cancer (ICD-10 codes C00-C97), ages 0-19 years for the world)*100
   Year = 2020
   Data source = Global Cancer Observatory, IARC, 2020
   https://gco.iarc.fr/today/home

5. Percentage of all childhood cancer deaths in the Latin America and Caribbean (LAC) region
   Definition = (Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 0-19 years for the country/ Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 0-19 years for the LAC region)*100
   Year = 2020
   Data source = Global Cancer Observatory, IARC, 2020
   https://gco.iarc.fr/today/home

6. Percentage of all childhood cancer deaths in the world (*calculated only for LAC region)
   Definition = (Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 0-19 years for the LAC region/ Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 0-19 years for the world)*100
   Year = 2020
   Data source = Global Cancer Observatory, IARC, 2020
   https://gco.iarc.fr/today/home

7. Percentage of all deaths among children and adolescents (1-19 years) that are due to Cancer
   Definition - Country = (Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 1-19 years for the country/ Number of deaths, all causes, ages 1-19 years, for the country)*100
   Year = most recent year available.
   - Argentina = 2018
   - Belize = 2016
   - Bolivia =2003
   - Brazil = 2019
   - Chile = 2018
   - Colombia = 2017
   - Costa Rica = 2019
   - Cuba = 2017
   - Dominican Republic = 2013
   - Ecuador = 2017
   - El Salvador = 2015
   - Guatemala = 2017
   - Guyana = 2014
   - Haiti = 2003
   - Honduras = 2013
   - Jamaica = 2014
   - Mexico = 2017
   - Nicaragua = 2018
   - Panama = 2018
   - Paraguay = 2017
   - Peru = 2017
   - Suriname = 2014
   - Trinidad and Tobago = 2012
   - Uruguay = 2017
   - Venezuela = 2014

Definition – LAC Region = (Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 1-19 years for the LAC region/ Number of deaths, all causes, ages 1-19 years, for the LAC)*100
Year = 2012 (latest available data with the largest number of countries (23 countries)

Countries included for this indicator = Argentina, Belize, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, El Salvador, Guatemala, Guyana, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Suriname, Trinidad and Tobago, Uruguay, and Venezuela.

Definition – South America Region = (Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 1-19 years for the South America region/ Number of deaths, all causes, ages 1-19 years, for the South America region)*100
Year = 2012 (latest available data with the largest number of countries (9 countries)

Countries included for this indicator = Argentina, Brazil, Chile, Colombia, Ecuador, Paraguay, Peru, Uruguay, and Venezuela.

Definition – Central America Region (includes Dominican Republic and Haiti) = (Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 1-19 years for the Central America region/ Number of deaths, all causes, ages 1-19 years, for the Central America region)*100
Year = 2012 (latest available data with the largest number of countries (9 countries)

Belize, Costa Rica, Dominican Republic, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, and Panama.

Definition – Caribbean Region (includes Guyana and Suriname) = (Number of childhood cancer deaths (ICD-10 codes C00-C97), ages 1-19 years for the Caribbean region/ Number of deaths, all causes, ages 1-19 years, for the Caribbean region)*100
Year = 2012 (latest available data with the largest number of countries (9 countries)

Countries included for this indicator = Cuba, Guyana, Jamaica, Suriname, and Trinidad and Tobago.
Data source = WHO Mortality Data (raw data files imported from WHO database)
Files accessed on September, 2021
https://www.who.int/data/data-collection-tools/who-mortality-database

8. Proportion of prioritized cancers

ALL= acute lymphoblastic leukemia
Burkitt=Burkitt's lymphoma
Hodgkin= Hodgkin's lymphoma
RB = retinoblastoma
Wilms = Wilms Tumor
LGG = low-grade glioma

Definition = (number of each one of the 6 prioritized cancers in the WHO Global Initiative for Childhood Cancer (Acute Lymphoblastic Leukemia, Burkitt's lymphoma, Hodgkin's lymphoma, Retinoblastoma, Wilms Tumor, and Low-grade glioma)/number of all childhood cancers)*100

Age range = 0-14 years

Regions = countries, subregions (South America, Central America, and Caribbean), and region (Latin America and the Caribbean)

Countries included in this analysis

Latin America and the Caribbean (n=32 countries): Argentina, Antigua and Barbuda, Bahamas, Barbados, Belize, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominica, Dominican Republic, Ecuador, El Salvador, Grenada, Guatemala, Guyana, Haiti, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Saint Kitts & Nevis, Saint Lucia, Suriname, Trinidad and Tobago, Uruguay, and Venezuela.

South America (n=10 countries): Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Paraguay, Peru, Uruguay, and Venezuela.

Central America (includes Dominican Republic and Haiti) (n=10 countries): Belize, Costa Rica, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Mexico, Nicaragua, and Panama.

The Caribbean (includes Guyana and Suriname) (n=12 countries): Antigua and Barbuda, Bahamas, Barbados, Cuba, Dominica, Grenada, Guyana, Jamaica, Saint Kitts & Nevis, Saint Lucia, Suriname, and Trinidad and Tobago.

Data source = PAHO/WHO Country Cancer Profiles – 2020
https://www3.paho.org/hq/index.php?option=com_topics&view=rdmore&cid=10473&item=cancer&cat=scientific_technical&type=4-cancer-country-profiles-2020&lang=en

Accessed on September, 2021

9. Annual trends in childhood cancer mortality

Indicator used = APC (Annual Percent Change) for trends in childhood cancer age-standardized mortality rates (0-19 years) for males and females

The annual percentage change is used to describe the magnitude of change in the trend on fitting a simple regression model to the log of the age-standardized mortality rate. It is the average annual rate of change in the age-standardized mortality rate over the time period selected.

Countries included in this analysis (period)

Argentina = 2000-2016
Barbados = 2000-2013
Belize = 2010-2016
Brazil = 2000-2016
Chile = 2000-2016
Colombia = 2000-2016
Costa Rica = 2000-2014
Cuba = 2000-2016
Dominican Republic = 2000-2013
Ecuador = 2000-2016
El Salvador = 2000-2014

Guatemala = 2000-2016
Mexico = 2000-2016
Nicaragua = 2000-2016
Panama = 2000-2016
Paraguay = 2000-2016
Peru = 2000-2015
Suriname = 2006-2014
Trinidad & Tobago = 2000-2012
Uruguay = 2012-2016
Venezuela = 2000-2013

Countries

Latin America and Caribbean (2000-2012) (21 countries): Argentina, Barbados, Belize, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, El Salvador, Guatemala, Mexico, Nicaragua, Panama, Paraguay, Peru, Suriname, Trinidad and Tobago, Uruguay, and Venezuela.

South America (9 countries): Argentina, Brazil, Chile, Colombia, Ecuador, Paraguay, Peru, Uruguay, and Venezuela.

Central America (includes Dominican Republic and Haiti) (2000-2012) (8 countries): Belize, Costa Rica, Dominican Republic, El Salvador, Guatemala, Mexico, Nicaragua, and Panama.

The Caribbean (2000-2012) (4 countries): Barbados, Cuba, Suriname, and Trinidad and Tobago.

Data source: IARC Cancer Mortality Database
https://www-dep.iarc.fr/WHOdb/WHOdb.htm

Color legends for results:

Yellow = annual trends, either positive or negative, were not statistically significant (95% CI includes the null hypothesis, i.e, APC=0)

Green = negative annual trends, statistically significant (95% CI does not include the null hypothesis, i.e, APC=0), i.e., there is a decrease in the childhood cancer mortality rates in the period.

Red = positive annual trends, statistically significant (95% CI does not include the null hypothesis, i.e, APC=0), i.e., there is an increase in the childhood cancer mortality rates in the period.

Cancer Registration and Survival

10. Number of active population-based cancer registries (PCBR)
    Levels = country, subregion, and region
    Data sources =
    a. [Progress, challenges and ways forward supporting cancer surveillance in Latin America.](#)
       Piñeros M, Abriata MG, de Vries E, Barrios E, Bravo LE, Cueva P, de Camargo Cancela M, Fernández L, Gil E, Luciani S, Pardo C, Zoss W, Bray F, Mery L. Int J Cancer. 2021 Jul 1;149(1):12-20. doi: 10.1002/ijc.33407. Epub 2020 Dec 14.
    b. [Advancing Reliable Data for Cancer Control in the Central America Four Region.](#)
       Piñeros M, Frech S, Frazier L, Laversanne M, Barnoya J, Garrido C, Gharzouzi E, Chacón A, Fuentes Alabi S, Ruiz de Campos L, Figueroa J, Dominguez R, Rojas O, Pereira R, Rivera C, Morgan DR. J Glob Oncol. 2018 Sep;4:1-11. doi: 10.1200/JGO.2016.008227. Epub 2017 Mar 8.
    c. https://caribbeancrh.carpha.org/The-Caribbean-Hub/Current-Status-of-Cancer-Registration-in-the-Caribbean
    d. Quesnel- Crooks S et al. Cancer registration in the Caribbean. Journal of Registry Management, 47(3): 161-169, 2020.

11. Percentage of population covered by Population-based cancer registries
    Levels = country, subregion, and region
    Data sources =

    e. [Progress, challenges and ways forward supporting cancer surveillance in Latin America.](#)
       Piñeros M, Abriata MG, de Vries E, Barrios E, Bravo LE, Cueva P, de Camargo Cancela M, Fernández L, Gil E, Luciani S, Pardo C, Zoss W, Bray F, Mery L. Int J Cancer. 2021 Jul 1;149(1):12-20. doi: 10.1002/ijc.33407. Epub 2020 Dec 14.
    f. [Advancing Reliable Data for Cancer Control in the Central America Four Region.](#)
       Piñeros M, Frech S, Frazier L, Laversanne M, Barnoya J, Garrido C, Gharzouzi E, Chacón A, Fuentes Alabi S, Ruiz de Campos L, Figueroa J, Dominguez R, Rojas O, Pereira R, Rivera C, Morgan DR. J Glob Oncol. 2018 Sep;4:1-11. doi: 10.1200/JGO.2016.008227. Epub 2017 Mar 8.
    g. https://caribbeancrh.carpha.org/The-Caribbean-Hub/Current-Status-of-Cancer-Registration-in-the-Caribbean
    h. Quesnel- Crooks S et al. Cancer registration in the Caribbean. Journal of Registry Management, 47(3): 161-169, 2020.

12. Number of specialized pediatric cancer registries

Data sources
[Advancing Reliable Data for Cancer Control in the Central America Four Region.](#)
Piñeros M, Frech S, Frazier L, Laversanne M, Barnoya J, Garrido C, Gharzouzi E, Chacón A, Fuentes Alabi S, Ruiz de Campos L, Figueroa J, Dominguez R, Rojas O, Pereira R, Rivera C, Morgan DR. J Glob Oncol. 2018 Sep;4:1-11. doi: 10.1200/JGO.2016.008227. Epub 2017 Mar 8.

IARC - International Incidence of Childhood Cancer – 3rd edition
https://iicc.iarc.fr/

*Nicaragua and Honduras = expanding activities from hospital-based cancer registry to population-based cancer registry

13. Mortality/incidence ratio

Levels = country, subregions, and region
Definition= Crude mortality rate for all childhood cancers, 0-19 years/Crude Incidence Rate for all childhood cancers, 0-19 years (rates are per million of children and adolescents)

Year = 2020
Data source = Global Cancer Observatory, IARC, 2020
https://gco.iarc.fr/today/home

Latin America and the Caribbean (n=31 countries): Argentina, Bahamas, Barbados, Belize, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominican Republic, Ecuador, El Salvador, Guadeloupe, Guatemala, Guyana, Haiti, Honduras, Jamaica, Martinique, Mexico, Nicaragua, Panama, Paraguay, Peru, Puerto Rico, Saint Lucia, Suriname, Trinidad and Tobago, Uruguay, and Venezuela.

South America (n=10 countries): Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Paraguay, Peru, Uruguay, and Venezuela.

Central America (includes Dominican Republic and Haiti) (n=10 countries): Belize, Costa Rica, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Mexico, Nicaragua, and Panama.

The Caribbean (n=8 countries): Bahamas, Barbados, Cuba, Guyana, Jamaica, Saint Lucia, Suriname, Trinidad and Tobago.

14. Net Survival rate

Definition = Net survival is **the survival that would be observed if the only possible underlying cause of death was the disease under study**.
Data source:

[Global childhood cancer survival estimates and priority-setting: a simulation-based analysis.](#)
Ward ZJ, Yeh JM, Bhakta N, Frazier AL, Girardi F, Atun R. Lancet Oncol. 2019 Jul;20(7):972-983. doi: 10.1016/S1470-2045(19)30273-6. Epub 2019 May 22.

Health System Response

15. Percentage of the WHO essential medicines to treat children with cancer that are included in the Essential Medicines List (EML) (country)
    Levels = country, subregion, region
    39 drugs listed as WHO essential medicines to treat children with cancer
    Indicator = (Number of WHO essential medicines to treat children with cancer listed in the Essential Medicines List of the country/Total number of WHO essential medicines to treat children with cancer (39))*100

    Data sources

    WHO Model List of Essential Medicines for Children 7th edition - 2019
    https://www.who.int/publications/i/item/WHOMVPEMPIAU201907

    WHO Global Essential Medicines
    https://global.essentialmeds.org/dashboard/countries

    Panama = national list of medicines
    http://www.minsa.gob.pa/destacado/comision-nacional-de-medicamentos-de-panama-conamep

    Guatemala = national list of medicines (lista básica de medicamentos)
    https://pesquisa.bvsalud.org/portal/resource/pt/biblio-1026872

    Latin America and Caribbean region = median value of all countries in the region
    South America = median value of all countries in the region
    Central America = median value of all countries in the region
    Caribbean = median value of all countries in the region

    Countries included in this analysis (n=32 countries): Antigua and Barbuda, Argentina, Barbados, Belize, Bolivia, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominica, Dominican Republic, Ecuador, El Salvador, Grenada, Guatemala, Guyana, Haiti, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Saint Kitts & Nevis, Saint Lucia, Saint Vincent & Grenadines, Suriname, Trinidad and Tobago, Uruguay, and Venezuela.

South America (n=10 countries): Argentina, Bolivia, Brazil, Chile, Colombia, Ecuador, Paraguay, Peru, Uruguay, and Venezuela.

Central America (includes Dominican Republic and Haiti) (n=10 countries): Belize, Costa Rica, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Mexico, Nicaragua, and Panama.

Caribbean (n=12): Antigua and Barbuda, Barbados, Cuba, Dominica, Grenada, Guyana, Jamaica, Saint Kitts & Nevis, Saint Lucia, Saint Vincent & Grenadines, Suriname, Trinidad and Tobago.

*Brazil = The financing of cancer drugs does not take place through the Pharmaceutical Assistance Components. The Ministry of Health and the State Health Departments do not directly provide cancer drugs. Hospitals qualified to provide Oncology assistance through SUS, whether public or private, for-profit or non-profit, are responsible for providing drugs for the treatment of cancer through their inclusion in chemotherapy procedures registered in the APAC-SIA subsystem (Authorization of Procedure for High Complexity of the Outpatient Information System) of the SUS and are reimbursed by the Ministry of Health according to the APAC code. These medications are standardized, purchased and prescribed by the hospital itself and must follow the protocols and therapeutic guidelines of the Ministry of Health, if any. All 39 cancer drugs included in the WHO Pediatric Essential Medicine List are approved by ANVISA.

16. Number of centers to deliver specialized care in pediatric oncology
    Data source = direct information provided by the Ministry of Health to PAHO

17. Ratio population (0-19 years)/centers
    Data source = Number of centers (provided by the Ministry of Health)/ Population =estimates UNDP – 2020

18. Universal Health Care Index for Service Coverage

    Definition = Coverage of essential health services (defined as the average coverage of essential services based on tracer interventions that include reproductive, maternal, newborn and child health, infectious diseases, non-communicable diseases and service capacity and access, among the general and the most disadvantaged population). The indicator is an index reported on a unitless scale of 0 to 100, which is computed as the geometric mean of 14 tracer indicators of health service coverage. The tracer indicators are as follows, organized by four components of service coverage: 1. Reproductive, maternal, newborn and child health 2. Infectious diseases 3. Noncommunicable diseases 4. Service capacity and access.

    Data source: https://www.who.int/data/gho/data/indicators/indicator-details/GHO/uhc-index-of-service-coverage

Year = 2017

Subregions and regions = median values

19. Presence of early detection program or guideline

    Data source = PAHO/WHO Country Cancer Profiles – 2020
    https://www3.paho.org/hq/index.php?option=com_topics&view=rdmore&cid=10473&item=cancer&cat=scientific_technical&type=4-cancer-country-profiles-2020&lang=en

    For subregions and region = % of countries with program or guideline.

20. Defined referral system

    Data source = PAHO/WHO Country Cancer Profiles – 2020
    https://www3.paho.org/hq/index.php?option=com_topics&view=rdmore&cid=10473&item=cancer&cat=scientific_technical&type=4-cancer-country-profiles-2020&lang=en

    For subregions and region = % of countries with defined referral system

21. Palliative care
    Data source = Atlas de Cuidados Paliativos de Latinoamérica – 2020
    https://cuidadospaliativos.org/recursos/publicaciones/atlas-de-cuidados-paliativos-de-latinoamerica/

Abbreviations and short names

LAC = Latin America and the Caribbean
NA = not available
ALL = acute lymphoblastic leukemia
Burkitt = Burkitt's lymphoma
Hodgkin = Hodgkin's lymphoma
RB= retinoblastoma

Wilms = WilmsTumor
LGG = Low-grade glioma
PBCR = population-based cancer registry
WHO = World Health Organization
EML = Essential Medicines List